MEETING MINUTES STATE CONSUMER AND FAMILY ADVISORY COMMITTEE JULY 8, 2004

<u>Present</u>: Jere Annis, Carl Britton-Watkins, Derl Bruce, Pete Clary, Zack Commander, Sandy DuPuy, Ron Huber, Kathleen Herr, Ed Masters, Doug Michaels, Ellen Perry, Barbara Richards, Katie Sawyer, Betty Stanberry, Amelia Thorpe, and Paula Wagner.

Absent: Ben Jones and Alex Vasquez.

DHHS Staff Present: Felissa Ferrell, Yolanda Hunter, Cathy Kocian and Ann Remington.

Facilitator: Beth Melcher.

Guests: Bert Bennett, Mark Botts and Holly Riddle.

1. Welcome

- ♦ A vote of 15 in favor (Barbara Richards was not present at time of vote) was taken to alter the agenda to include Bert Bennett, DHHS-DMH, who will make a presentation on the Real Choice Grant. This is a housing grant for people with disabilities.
- ♦ Representatives from the Mental Health Commission were unable to attend this meeting to present to and dialogue with the SCFAC members. Mr. Pender McElroy, Chairperson of the Mental Health Commission, has requested that he be placed on the agenda at the August meeting.
- ♦ It was requested that the minutes reflect a concern that the member of the Commission had a one month notice of this meeting and was still unable to be present.

2. Approval of Minutes

♦ A motion was made, seconded and passed unanimously that the minutes from the June 8, 2004, meeting be approved.

3. Terms of Office Identified

- ♦ The SCFAC member terms are one, two, and three years.
- ◆ Committee members can be reappointed by the DHHS Secretary, Carmen Hooker-Odom.
- ♦ The drawing to determine the terms of office for the members absent today will be done in alphabetical order following the drawing for the terms of those present.
- ♦ The vacant adolescent positions could be posted on the web. However there are no atlarge seats, so the adolescents must be members of a local CFAC group.
- ♦ SCFAC Term Limits:

One Year Term	Two Year Term	Three Year Term
Zack Commander	Doug Michaels	Sandy DuPuy
Pete Clary	Ellen Perry	Katie Sawyer
Amelia Thorpe	Ron Huber	Ed Masters
Paula Wagner	Barbara Richards	Betty Stanberry
Carl Britton-Watkins	Kathleen Herr	Jere Annis
Ben Jones	Derl Bruce	Alex Vasquez

4. Developmental Disability Presentation by SCFAC Members

- ♦ Developmental Disabilities (DD): Ellen, Pete and Barbara (with the help of Holly Riddle) designed a PowerPoint presentation. Each member received a copy of the presentation.
- ♦ The Federal Definition of DD: "severe, chronic disabilities attributable to mental and/or physical impairment that appear before age 22 and are likely to continue indefinitely." These disabilities result in "substantial limitations" in three or more areas:
 - Self-care.
 - Receptive and expressive language,
 - Learning,
 - Mobility,
 - Self-direction.
 - Capacity for independent living and/or
 - Economic self-sufficiency.

Anyone who meets the definition must also have a "continuous need for individually planned and coordinated services."

- There are two federal funding streams for people with DD:
 - Intermediate Care Facility (ICF) MR/DD
 - 1. Funds many group homes and large Developmental Centers.
 - 2. The money is tied to the program; if you leave the program the money stays with the program and does not follow the person.

• CAP-MR/DD

- 1. The money does follow the person to home, work, and to the community.
- 2. Waivers vary from state to state.
- ♦ One of the biggest issues facing NC consumers and families deals with the fact that agencies receive the funding and then employ workers who are not trained to give services properly.
- ♦ Comments were expressed regarding the amount of time it takes to get approval for services and that a 6 month wait is "ridiculous."
- Another issue relates to where and with whom people will live.
- ◆ As the SCFAC reviews Policies and Procedures they will want to pinpoint the specifics of systems issues (i.e., trained workers, living options, and approval time).
- ♦ Grass-root groups in NC:
 - RANE- Real Advocates Now Emerging,
 - TASH- formerly stood for The Association of Severely Handicapped,
 - NC DAN,
 - ADA Network,
 - Association of Self-Advocates and
 - CFACs Consumer and Family Advisory Committees.

5. Mental Health Disability Presentation by SCFAC Members

- ♦ Mental Health Disability Group: Amelia, Kathleen, Paula, Ed, and Zack gave a verbal presentation on this disability area.
- ♦ According to a SCFAC member, there are three functioning levels of people with mental illness. One group is very debilitated and non-functioning. The second group might be involved clubhouses and helps out with meals, cooking, cleaning, and other various responsibilities. The third group has jobs and might be fully self-supporting.

- ♦ The stigma for people with a diagnosis of a mental illness is still quite great. The perceptions associated with this illness usually are that these people are either not very smart or that they are "retarded."
- Psycho-social clubhouses have many opportunities available for persons with mental illness. Job training/placement and work with a job coach are other options available to people with mental illness.
- ♦ The fears and concerns surrounding this disability include questions such as "who will service me, counsel me, be my psychiatrist, or provide me with adequate casemanagement?" The consumers view these professionals as their friends and confidants.
- ♦ It is very important for people with Mental Illness to get involved and feel a part of life and recovery.
- ♦ Gaps in services are occurring in the service system for people with mental illness today. One method of obtaining more information about these gaps might be to do a survey in DSS or the school system. Once all gaps are disclosed, evidence-based models could be utilized to close the gaps.
- The reality is it will take a long time to close the gaps.
- The number of young people with mental illness is a rising concern in NC.
- ♦ The services are very limited in NC. There is one program in NC for female adolescents that has 8 slots for treatment. That represents 1 female child for every 2-3 area programs across the state. The other option is to put the child in the juvenile justice system.
- ♦ It is not recommended to put juvenile justice and mentally ill youth together. Not all mentally ill people have behavioral problems.
- ♦ Financing can be received from Medicaid if the child is institutionalized for over 13 months. Parents have been known to give up children just so the child can receive treatment.
- ♦ Only 2 SCFAC members are aware of the Child and Community Collaboratives in the North Carolina.
- ♦ The four mental illnesses are major depression, bi-polar disorder, obsessive-compulsive disorder, and schizophrenia.
- ♦ 1/3 of the homeless population has mental illness and at one time belonged to a family.
- ♦ The average person is sick for 10 years before they seek treatment. This is why prevention and education are so vital and necessary.
- ♦ There are major concerns regarding parity insurance companies not covering treatment for mental illness in the same way physical health problems are covered.
- ◆ The suicide rate among the mentally ill is high and could be reduced if people received help earlier.
- ♦ NC does not recognize temporary insanity, so a person having been diagnosed as temporarily insane would not receive treatment for a mental illness.
- Borderline disorders are very difficult to diagnose and involve extreme mood swings.
- ♦ It is important to remember that each mentally ill person's situation is different as is the situation for their family. Therefore, the SCFAC needs to approach these issues with ways that will make a difference.

6. Co-Occurring and Substance Abuse Disability Presentation by SCFAC Members

♦ Co-Occurring and Substance Abuse group: Doug, Carl, Sandy and Derl requested to make their presentation in August. The committee approved the request.

- Every life is affected by substance abuse whether it be in our neighborhoods, family, co-workers, bosses, or drivers on the road.
- ♦ Addiction is a shame-based disease which carries with it a great deal of stigma which makes people afraid to self-disclose or even talk about it.
- ♦ SA is an addiction problem not a mental problem. Some people with MI and DD have been known to self-medicate with alcohol and drugs.

7. State-CFAC Rules of Operation (Code of Conduct)

- ♦ The members of the sub-committee (Jere Annis, Zack Commander, Doug Michaels [Point Person] and Ellen Perry) gave a report of their discussion surrounding the rules.
- ◆ The committee chose to accept the following Code of Conduct with the understanding that it will be revisited in 3 months by the group:

♦ Value and Purpose for Meeting

Members should attend each meeting unless their absence is unavoidable.

The group should follow the agenda.

Discussion should focus on one topic at a time.

♦ Value Time

Meetings should begin and end on time.

Members should be concise with their input.

Members should be prepared for each meeting.

The group should keep discussion relevant to the issue being discussed.

♦ Promote Team Feeling

The group should encourage participation and creative ideas.

The group should solicit input from all members—a few should not be allowed to dominate the meeting.

All ideas should be considered.

♦ Demonstrate Respect for All Participants

The ideas and viewpoints of all members should be valued.

Individual agendas should be put aside.

One person speaks at a time - avoid side conversations.

All members should listen "actively."

Thought and consideration should be given before judging.

Put phones on silent or vibrate mode.

♦ Create a Harmonious Atmosphere

Profanity and temperamental outbursts should be avoided.

Members should be positive and constructive in interactions and feedback.

Hostile humor should be avoided.

♦ Ensure Closure and Strive for Consensus

Action items should be defined.

Assignment of responsibility for action items and the establishment of timelines should occur.

Follow-up on items should occur.

No anonymous information will be addressed at meetings. We won't accept information for processing that people won't take ownership for.

8. The Development of By-laws

- Beth Melcher distributed a line-by-line list of comments made by SCFAC members.
- ♦ Mark Botts, Institute of Government, was present to assist the group with the understanding of terms (i.e., shall, will, should, must, may, etc.) and by-laws in general.

- ◆ The SCFAC reviewed pages 1-3 and will finish the review of pages 4-6 at the August meeting.
- ◆ The State Plan does not mention anything about by-laws for SCFAC, but it does for the local CFAC groups. The SCFAC is very supportive of by-laws for this group.
- Revisions were made to the by-laws and a final corrected version will be produced once changes are incorporated.

9. Confidentiality

- Anyone can use an audio or video tape recorder at the meetings.
- The voting is done in front of everyone and can be recorded.
- ♦ The only time the group can go into closed session is to discuss privileged or confidential information as covered under law. A motion must be made and passed in order to go into closed session.
- ♦ The group decided they will draft a policy on confidentiality once the chairperson is elected and they can discuss this in further detail.
- Since the Secretary appointed the committee, the identities of the members are already a matter of public record and are posted on the web. There is no exception to this.

10. Nominating Sub-Committee

- ♦ Sandy DuPuy, Kathleen Herr and Pete Clary are the members who will be working on the nominating sub-committee.
- The members of this committee cannot stand for an office.
- ♦ Members must let Sandy DuPuy know by July 23, 2004 who their choice of candidates are for the Chair and Vice-Chair positions.
- ♦ Members may self-nominate.
- A 2 minute presentation will be given by all nominated persons at the August Meeting.

11. Central Regional CFAC Meeting

- ♦ Felissa Ferrell announced the Regional CFAC meeting that will be held July 15, 2004 in the Winston-Salem area.
- ♦ People wishing to attend can pay \$5.00 for a box lunch at the door or may bring their own lunch.

12. Research Triangle Park Conference

- ♦ Beth Melcher announced a Conference scheduled for August 25, 2004. It is jointly sponsored by NAMI and the NC Science Research Project.
- ◆ The Conference will include information on "how to promote effective services in your community."
- ♦ Laurie Coker and Carl Britton-Watkins will facilitate a discussion at the end of this conference on "how to take information back to your community."

13. Real Choice Grant

- ♦ Bert Bennett, Psychologist and staff member of DHHS-DMH, gave background information on this grant.
- ◆ There has been an active partnership between DHHS and the NC Housing Finance Agency.

- ♦ 10% of units will be set aside for persons with disabilities and will be interspersed throughout housing units.
- ♦ A variety of agencies such as Easter Seals, Social Services and Mental Health can be lead agencies.
- ♦ These units must be SSI affordable (\$170-180 per month rent).
- It is the goal to work with consumers and providers to increase affordable housing.
- ♦ The SCFAC group voted in favor of signing a letter of support for the Division with hopes they will receive this grant. The vote was 14 in favor of this motion (Doug Michaels and Pete Clary were not present at the time of voting).

14. Next Meeting

- ♦ The next meeting is scheduled for August 12, 2004 from 9:30-3:30 pm at the NC Council on Developmental Disabilities in Raleigh.
- The lunch menu was sent around with a sign-up sheet for the August meeting.

15. Agenda

- ♦ By-Laws
- ♦ Nominating Sub-Committee
- ♦ CTSP Funds and Child Collaboratives
- ♦ Co-Occurring and Substance Abuse
- Presentation and dialogue with Pender McElroy from the MH Commission.

Directions to the NC Council on Developmental Disabilities



Take I-440 (Beltline) to Exit 5 - Lake Boone Trail. Turn towards Rex Hospital at the light. Make the first left (Corner of Lake Boone Trail and Myron Dr.). You will see Building 3801. The NC DD Council is located on the second floor, Suite 250.

NC Council on Developmental Disabilities 1-800-357-6916